ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

February 1995

A Response to "So What Gets You Through?"

By Jim Hayes, a Founding Member of MCC Boston

Ravi Verma's reflections [in the article "So What Gets You Through?" in the November/December, 1994 issue of ALERT] were most valuable, as I found myself identifying with so many of his reactions and experiences.

My first response to his question is that God gets me through: possibly simplistic sounding, but true for me. I offer praise and thanks to God for abundant and continuing blessings on this journey. At times when my faith was weak and my suspicions strong, after prayer with God, I was able to:

*inform my brother of my HIV-positive status and receive his love and support;

*inform my supervisor and the executive director of my agency of my status and receive their love and support;

*survive four hospitalizations and substantial loss of sight with surprising equanimity and sense of satisfaction and gratefulness that what could be done was done, and most of it correctly.

A "positive attitude" gets me through. I've never been an optimist by nature, but AIDS has led me through some changes. I helped start MCC Boston in 1972; I became infected with HIV in 1986 (I know that because of previous negative HIV tests) - MCC Boston has lasted 24 years through many ups and downs, and I take the attitude that Jim Hayes can similarly endure! As I encounter each problem or illness I try not to whine (it is perfectly OK to cry!) I try to identify my range of choices to solve each problem and actively participate in deciding which choice will apply to me.



Mr. Jim Hayes

An active partnership with an excellent physician helps get me through. For many years I have worked with the same primary care physician, Andrew Modest. He's very smart, very quick-thinking, very well-informed on HIV/AIDS, and gay sensitive. We work with each other as people, and he encourages my participation in decision-making and solution-finding. He consistently advises me of what, in his opinion, would be most healthy for me, but respects my right to make the ultimate decision.

(see Jim Hayes, page 3)

UFMCC Reps Meet With C-Ran and CDC Officials

Rev. Herbert Evans and Rev. Steve Pieters represented UFMCC AIDS Ministry when the U.S. Council of Religious AIDS Networks (C-RAN) met with officials of the Centers for Disease Control (CDC). The meeting, which took place December 15 and 16, 1994 in Atlanta, Georgia, focused on ways in which denominational AIDS ministries and other faith groups could form partnerships with the CDC in HIV prevention and risk reduction activities.

The first day of the meeting, members of C-RAN met on their own to discuss needs and strategies. The second day, other religious organizations which are not members of C-RAN joined with council members in meeting with numerous officials from the CDC.

CDC representatives included Dr. James Curran, Associate Director for HIV/AIDS; Priscilla Holman, the Chief of the National Private Sector Partnerships of Dr. Curran's office; and Dorothy Triplett, Assistant Director for Minority and Other Special Populations, also from Dr. Curran's office.

Other religious organizations participating included the National Evangelical Association, the AIDS Task Force of the Seventh Day Adventists, and the Congress of National Black Churches.

Discussions included the role of religious organizations in HIV/AIDS prevention, as well as recommendations and next steps for a national strategy to engage communities of faith in HIV/AIDS prevention, including technical assistance needs to be met by public health or by the religious organizations themselves. CDC representatives were interested in hearing what the faith communities present were doing in HIV/AIDS prevention, what they would like to do, and how the CDC could help them. ▼

Benevolence Fund Really Helps!

By Rev. Don Magill

Living with AIDS and dealing with the medical aspects of the syndrome is difficult in and of itself. Struggling with and managing the daily, weekly and monthly opportunistic infections that arise due to a weakened or non-existent immune system, constant trips to the doctor, laboratory tests, and so on, are enough to truly test one's stamina and faith without having to also deal with the myriad of other issues associated with AIDS. As an example, sometimes I don't know which is worse - dealing with the deterioration of my health and the medical problems associated with that, or dealing with government red tape.

After living on social security disability benefits for eighteen months, I finally became eligible for Medi-Care which meant that I would no longer have "out-of-pocket" medical expenses. As a result, the Social Security Administration had to re-evaluate and update my case and in doing so, they discovered that the company who did my taxes in 1991 failed to file my self-employment tax. Consequently, they notified the U.S. Internal Revenue Service who then said that I owed hundreds of dollars in back taxes plus interest and penalties. Unfortunately, this occurred at the same time that I was diagnosed with MAI and thus, I also had to deal with accepting this new opportunistic infection and adding two more medications to my daily routine. And I had to re-apply for food stamps and medical coupons.

As you can imagine, I was in a predicament because the self-employment taxes that I paid into the Internal Revenue Service over the years while I was pastoring are what the Social Security Administration now uses to figure the monthly amount of my disability benefits and Medi-Care payments. Consequently, if these back taxes weren't paid, I might lose my Medi-Care benefits in addition to the Social Security Administration having to reduce my monthly disability payment which could ultimately affect the amount of food stamps and other government assistance that I receive. Needless to say, I didn't know what to do or how I was going to pay these back taxes on the small amount of disability benefits that I receive each month!

Fortunately, I decided to write the Rev. Steve Pieters, to whom I explained my predicament and requested assistance from the UFMCC Benevolence Fund. I figured that I had nothing to lose in asking but everything to gain. Well, praise God, on the same day that the UFMCC received my letter, I received a phone call from Steve stating that the UFMCC Benevolence Fund would pay my back taxes so that I could get my Medi-Care benefits. Needless to say, this was truly a blessing as these funds helped to alleviate one more struggle in living with AIDS. Consequently, I can now go on with my life again and re-focus my energy back on health care and maintenance.

Won't you and/or your church consider making a donation to the UFMCC Benevolence Fund? By doing so, you will help the Fellowship ensure that there are always funds available for emergencies. In addition, you will be helping clergy with HIV/AIDS alleviate stress and anxiety, and that can prolong life. Thank you. ▼

CBO Directory Published by CDC

The U.S. Centers for Disease Control National AIDS Clearinghouse has published *National Organizations Providing HIV/AIDS Services, A Directory for Community-Based Organizations.* The CDC National AIDS Clearinghouse (CDC NAC) is the CDC's national reference, referral, and distribution service for HIV/AIDS related information. The CDC NAC offers a variety of services including: reference and referral, publications distribution, resource centers, and an electronic bulletin board.

The CDC NAC staff prepared this directory to give quick access to national HIV/AIDS service organizations. Each entry in the directory includes the name of the organization, a brief discription, telephone and fax numbers (if available) and other related information.

The Clearinghouse has recently published another new book, *HIV/AIDS Information Services: Profiles of Successful Services Plus Advice for Starting Your Own.* This book includes profiles of 11 HIV/AIDS information services as well as samples of newsletters, pathfinders, bibliographies and more. You may order a free copy of this book or the update *Catalog of HIV and AIDS Education and Prevention Materials* by calling 1-800-458-5231 (TDD/deaf access: 1-800-743-7012).

Clearinghouse staff members serve a diverse network of people who work in international, national, state, and local settings. ▼

Methodists Publish Annotated Bibliography

The Health and Welfare Ministries Program Department of the United Methodist Church has published an updated and expanded edition of "HIV/AIDS Resources for People of Faith: An Annotated Bibliography." Written and compiled by the Rev. Nancy A. Carter, categories include:

* curriculum resources for congregational study,
* books that give a Biblical, theological basis for HIV/AIDS ministries,
* books for meditation and planning worship services,
* books on counseling, social work, and pastoral care,
* books about psycho-social and spiritual support for individuals and groups,

(see Methodists Publish, page 4)

General Conference XVII

Atlanta, Georgia
July 23-30, 1995

"All Things Are Possible" (Mark 9:23)

The registration packets for General Conference XVII have been mailed out. If you have not received a packet and would like to have one mailed to you, please fill in your name and address below and return this card to: UFMCC GCXVII, 5300 Santa Monica Blvd., #304, Los Angeles, CA 90029; or call (213) 464-5100.

NAME _____

ADDRESS _____

CITY _____ ST/PROV _____

ZIP/PC _____ COUNTRY _____

Strategic Planning for AIDS Service Organizations

The U.S. National Minority AIDS Council (NMAC) has published a manual entitled *Strategic Planning for AIDS Service Organizations: A Practical Guide and Workbook.* Copies are free to members of NMAC. Non-members may purchase copies for $15.00 from the Technical Assistance Department of NMAC, 300 Eye Street, NE, Suite 400, Washington, DC 20002-4389.

This workbook is an excellent tool for planning efficient and effective work in the ever-changing environment of HIV/AIDS work. According to Manuel Magaz, the Director of Technical Assistance for NMAC, "NMAC's strategic planning workbook has been produced at a critical time for the AIDS movement. We are seeing many changes and facing many challenges. The process of strategic planning stresses the importance of making decisions that will ensure our ability to adequately and appropriately respond to these changes." ▼

UFMCC AIDS Ministry Task Force Meets

The UFMCC AIDS Ministry Long-Range Task Force met in Los Angeles on January 13-14, 1995. Rev. Jim Mitulski, the new chair of the Task Force, led the group in reviewing AIDS Ministry goals and objectives and the job description of the Field Director. Also, the Task Force discussed programming for General Conference XVII in Atlanta, and talked extensively about trends in HIV/AIDS, and implications for MCC's around the world. The group brainstormed ideas for future programming that would particularly benefit the local church.

Members of the Task Force include the Chair, Rev. Jim Mitulski, Rev. Elder Don Eastman (Board of Elders liaison to the UFMCC AIDS Ministry), Rev. Dr. Lori Dick, Ms. Jane Rogers, Mr. Larry Young, Rev. Herbert Evans, Rev. Jorge Sosa and Rev. Paul Tucker. Unfortunately, Sosa and Tucker were unable to attend this meeting. Rev. Steve Pieters serves as staff for the Task Force, and Ravi Verma, Director of Administration for UFMCC and Rev. Pieters' supervisor, also attended the meeting.

The Department of People of Colors met at the same time and led the two groups in worship and communion, and everyone met for lunch to discuss their overlapping work. ▼

Jim Hayes

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For example, when I was taking dilantin for seizure control plus three antivirals (AZT, ddI, and Trental), the stress on my liver was substantial. He suggested that I consider eliminating bourbon manhattans from my diet. I honored that advice by substantially cutting down but not eliminating. As I added meditation, massage, and an improved sex life to my schedule, my CD4 counts and general health have improved to the point where I now take only the dilantin and the occasional manhattan!

Another example: as an executive at my company I am aware of the annual increase in the cost of the health insurance premium we pay for each employee. One day when I arrived at Andrew's office in considerable pain from a leg infection, he was alarmed and said that immediate hospitalization was necessary. His plan was to send me by ambulance from his office to the hospital at a cost of $300. I proposed a plan more comfortable to me: he let me take a taxicab for $7. On the other hand, the hospital once planned to discharge me at 10 pm, to be visited at home by a home infusion nurse at midnight...I called Andrew to delay discharge until daylight, although I knew the extra night cost $500. So - cooperate, negotiate, but don't capitulate!

Support groups get me through: a good one at Massachusetts General Hospital for two years, and a great one at AIDS Action Committee, which I have attended every Thursday night for four years with few absences. Learn from other people's journeys and soak up useful information whenever you can.

Reading and research gets me through...as a law school graduate I'm used to the Latin-root big words, and I visit the Boston University Medical School library weekly to read the AIDS journals. I also keep track of Project Inform, AIDS Treatment News, ALERT, etc. Stay updated and well-informed!

Being an activist helps get me through. For me, activism is much more satisfying than staying home on the couch worrying about each ache and pain. As my doctor says, some of the aches aren't AIDS-related at all...they come because I'm getting old (I'll turn 46 in March). So, I serve on the Board of Directors of AIDS Action Committee, one of the six largest AIDS service organizations in the country. I've been appointed by the Mayor of Boston to the Ryan White AIDS Services Planning Council. I serve on the AIDS/HIV Consumer Advisory Board at Fenway Community Health Center. I served on our state Department of Public Health AIDS proposal review committee, and our City Task Force on Clean Needle Exchange which succeeded in persuading our state legislature to approve an experimental needle exchange program for Boston IV drug users. I lobbied at our State House, with IV drip running, for increased state funding for AIDS services.

Doing what I can for other people gets me through. Anticipating years ago that I or some other employee might get AIDS, I proposed to our company board of directors that they join the corporate consortium on AIDS, and adopt its ten principles regarding AIDS in the workplace. They did. Nine months later, my principle assistant was diagnosed with AIDS and all the favorable policies were comfortably in place...I helped him move from apartment to apartment to hospice and helped care for him and love him until he died. My ex-lover's 26-year-old nephew died last week from AIDS...we stayed with him and nursed him too.

I now know 104 relatives, ex-lovers, friends, and acquaintances who have died of AIDS related illnesses...but what gets me through is not dealing with the enormity and totality of it, but dealing with each lovely person, one at a time. Each one reach one and teach one, and don't give up hope.

Last and not least, MCC friends and mentors help get me through. Many years ago, when I was at a turning point regarding MCC inaction, a conversation with the Rev. Ron Russell-Coons inspired me to look at the world in quite a different way. Books and sermons by the Rev. Stephen Pieters have been a big help; and I've benefited by work done by the Rev.'s Steve Carson, Jim Mitulski, and Tim Koch. I believe that MCC could do substantially more, and that we need (all of us, not just the HIV-positive) to talk about this crisis a lot more, but I am very grateful for the good work already done! ▼

Prevention Funds for Gays increase in New Zealand

Rev. Elder Wilhelmina Hein reports that New Zealand's Public Health Commission funding for prevention of HIV transmission among men who have sex with men has been increased from $450,000 in 1994, to $600,000 in 1995. The money has been granted to the New Zealand AIDS Foundation (NZAF). In addition to the education and prevention work already in place, the new money will enable NZAF to target provincial areas and young men who have sex with men. The money will also enable NZAF's Maori Youth Project to continue.

Unfortunately, the increase in moneys for prevention will be provided by decreasing funds for information services such as the national AIDS Hotline and the reference library of NZAF. The Public Health Commission has also established a policy of no longer funding clinical and support services. NZAF and other service providers are being encouraged to seek that kind of funding through the four Regional Health Authorities. NZAF leaders are hopeful about their negotiations with the regional health authorities, although prevention funds are still below the $750,000 hoped for.

In addition, the "Hero Project" will also receive $22,000 to target young men who have sex with men, as well as those with multiple partners. The Hero Project won "the supreme award" in the New Zealand 1994 AIDS Media Awards. The award was given for the Hero 4 party, parade, and festival, events which are "inspiring, flamboyant" methods of educating New Zealanders about HIV risk reduction. ▼

A Memorial Song From A Loving Mother

The poem below, in both English and Spanish, was written by the mother of Jose Benito Degollado. Benito was a friend of Jim Hayes of MCC Boston. Jim reports that Benito's mother flew up from Mexico, wrote the song, and sang it at his funeral.

It is offered in the spirit of sharing the experience of grieving with faith.

Methodists Publish...

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* books for or about women and HIV/AIDS,
* books of interest to a variety of families,
* books for or about children or teens and HIV disease,
* pamphlets, brochures, posters, and videocassettes about HIV/AIDS.

The annotated bibliography may be ordered by writing Rev. Nancy Carter, Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, New York, NY 10115. Phone: 212-870-3909; Fax: 212-749-2641. Ask for HIV/AIDS Ministries Network Focus Paper #26. ▼

Written for "Jose Benito Degollado"

April 22, 1962 - January 11, 1995

(In Spanish and English)

Rainbow Pin

I shall praise the grace of God for I carry my cross
And I carry my rainbow pin, and there is no other pin
As beautiful and colorful as mine.
I sing my humble song to cheer your souls
For singing takes my pain away and there is no other song
As beautiful and colorful as mine.
I am happy, for my life is full of grace
When Christ is with me, my life is complete
God fills my life like a garden full of flowers
And there is no other life
As beautiful and colorful as mine.
I praise and love my Christ for He is my life and treasure
Up above, in the sky, He will call for me
And the rest of my life I will spend with Him.
I shall praise the grace of God for I carry my cross
And I carry my rainbow pin, and there is no other pin
As beautiful and colorful as mine.
My love is red, green is my hope, orange brings me patience
Blue is the sky, the sky of God, violet brings happiness,
Yellow brings peace.
And I would like to tell you
That my son Benito is this colorful rainbow
Giving us love, hope, patience, happiness
And he leaves us with beautiful memories,
Beautiful memories, in all our hearts.

Broche De Amores

Voy a aumentar la gracia de Cristo,
Porque yo traigo mi crucifijo,
Tambien yo traigo el Broche De Amores,
Y no hay otro broche tan lindo Y bonito como mis colores.
Y voy a cantar mi humilde cancion Para alegrarles sus corazones, Porque cantando se acaban dolores,
Y no hay otro canto tan lindo Y bonito como mis colores.
Y ya soy feliz, proque vivo en gracia, Si traigo a mi Cristo nada me falta, Y Dios me corto mi jardin de flores,
Y no hay otra vida tan linda Y bonita como mis colores.
Quiero a mi Cristo, lo amo, lo adoro El es mi vida, tambien mi tesoro Y alla en alto cielo El me va a buscar
Y el resto de mi vida, con El voy a estar.
Voy a aumentar la gracia de Cristo, Porque yo traigo mi crucifijo, Tambien yo traigo el Broche De Amores,
Y no hay otro broche tan lindo Y bonito como mis colores.
Rojo es amor, verde esperanza, Anaranjado paciencia me da Azul es el cielo, el cielo de Dios
Violeta la felicidad, Amarillo la paz que el me da.
Y quiero contarles que mu hijo Benito,
Les representa estos colores,
Dandonos amor, esperanza, paciencia, felicidad,
Y nos deja recuerdos hermosos,
Recuerdos hermosos, en cada corazon.